Priorities to Improve Dementia Caregiving in Chinese Immigrant Families: Report of a Caregiver Workshop

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Introduction

- Linguistically diverse caregivers are a growing but under-recognized dementia care workforce in the U.S.
- There is a continued shortage of culturally and linguistically responsive dementia caregiving interventions for older U.S. Chinese immigrants with limited English proficiency.
- To address the unmet needs of Chinese-speaking caregivers, integrating caregivers' input is vital to studies to ensure that research aligns with their experiences.

Objective

To identify Chinese immigrant caregivers' priorities and preferences for dementia care services and interventions

Methods

- **Design:** Qualitative, focus group study
- **Setting:** An in-language workshop for Chinese family caregivers about dementia
- **Recruitment:** Eligible participants were identified and recruited from the local Chinese Community Health Plan, then invited by the community partner
- **Data collection:** During the workshop, caregivers identified their needs in surveys, then discussed with one another in the focus group. Discussion was conducted in a semi-structured manner.
- **Analysis:** Focus group discussions were recorded, transcribed and analyzed using thematic approach

Participants

- N = 10 Chinese-speaking caregivers
- Mean age = 73.7 (SD = 7.9), eight women
- Relate to care recipient: 7 spouses, 2 children, 1 parent
- All lived with care recipients
- English proficiency: 2 not at all, 5 not well, 3 well
- Nativity: 9 foreign-born, 1 U.S. born

Funding and Contact

Results

Chinese American immigrant families prioritized information and practical support for dementia caregiving in four areas:

Management of behavioral and psychological symptoms of dementia (BPSD)

- "My biggest challenge is my mother wants to do everything but does not know what she is doing. Sometimes she does things that could be dangerous...for example she climbed to the roof to sweep the leaves. I was not at home. I could not monitor her. This frustrates my father."

Communication with care recipients and other family members

- "Sometimes, my mother likes to bring up topics that are sensitive and can easily lead to arguments at home...Of course, she is my mother, and as [her] child, it is easier for us to understand. But when you have others, not to mention my wife, just my brother-in-law, they always argue for this same problem."

Care for caregivers' physical and mental health

- "I take care of him, [but] in return I developed depression. Because day and night, he scolds at people. Since I need to take care of him, I do not have energy. I can't sleep well. When I am awake, I cannot go back to sleep. I need to take sleep medicine now."

Connect to in-language community resources

- "I do not know which is better – send her to nursing home or have her taken care of by relatives at home? I go back and forth. I have been asking to see whether there are nursing homes/senior homes for dementia."

Discussion

- **Recommendations:** Future research and interventions for Chinese-speaking immigrant caregivers in the U.S. are recommended to prioritize BPSD management skills training, adopt a family-centered approach and include family outcomes, improve access and quality of healthcare services specifically for caregivers, and address service barriers via community-clinic partnerships, community outreach, and bilingual lay health workers.
- **Limitations and future directions:** Given the exploratory nature of this qualitative study and the small convenience sample, the findings have limited generalizability, particularly limited to Chinese American immigrant families living in large urban cities. Future studies with larger sample sizes will allow for more representative and transferable results.